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Citation for published version:

Brown, M, Mitchell, B, Quinn, S, Boyd, A & Tolson, D 2020, 'Meaningful activity in advanced dementia', *Nursing Older People*. <https://doi.org/10.7748/nop.2020.e1171>

Digital Object Identifier (DOI):

[10.7748/nop.2020.e1171](https://doi.org/10.7748/nop.2020.e1171)

Link:

[Link to publication record in Edinburgh Research Explorer](#)

Document Version:

Peer reviewed version

Published In:

Nursing Older People

Publisher Rights Statement:

This is the accepted version of the following article: Brown, M., Mitchell, B., Quinn, S., Boyd, A., & Tolson, D. (Accepted/In press). Meaningful activity in advanced dementia. *Nursing Older People*. This is not the version of record, which has been published in final form at: <https://journals.rcni.com/nursing-older-people/evidence-and-practice/meaningful-activity-in-advanced-dementia-nop.2020.e1171/abs>

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Nursing Older People

Meaningful activity in advanced dementia

--Manuscript Draft--

Manuscript Number:	NOP1171R3
Article Type:	Article - if in doubt use this one
Full Title:	Meaningful activity in advanced dementia
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Abstract:	When the person with advanced dementia cannot communicate verbally and has limited movement, activities that he or she once enjoyed may no longer be possible. This limits opportunity for self-realisation and can lead to a preoccupation within advanced dementia care about the routines associated with the maintenance of comfort and nourishment, at the expense of contentment and moments of fulfilment (Smith et al., 2018). Such a narrow focus can lead to changes in behaviour indicating boredom, frustration and distress. Yet, there are opportunities for a more creative approach to activity that can be adapted to the person's changing needs and the human desire to feel connected and engaged. Examples of these evidence informed creative interventions for people living with advanced dementia care include music, doll focussed activity, animal assisted interventions, complementary therapy approaches and multisensory experiences, such as Namaste. These activities can engage the person with advanced dementia in a close connection with another human being through individualised and sensory based care.
Keywords:	Advanced dementia; meaningful activity; sensory care; embodiment; Nursing
Additional Information:	
Question	Response
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What is the word count of your document including references but excluding the abstract?	4190
What is the word count of your document excluding both references and the	2819

abstract?	
Author Comments:	this is paper three of a series of five on advanced dementia

Paper 3. Meaningful Activity in Advanced Dementia

Abstract

When the person with advanced dementia cannot communicate verbally and has limited movement, activities that he or she once enjoyed may no longer be possible. This limits opportunity for self-realisation and can lead to a preoccupation within advanced dementia care about the routines associated with the maintenance of comfort and nourishment, at the expense of contentment and moments of fulfilment (Smith et al., 2018). Such a narrow focus can lead to changes in behaviour indicating boredom, frustration and distress. Yet, there are opportunities for a more creative approach to activity that can be adapted to the person's changing needs and the human desire to feel connected and engaged. Examples of these evidence informed creative interventions for people living with advanced dementia care include music, doll focussed activity, animal assisted interventions, complementary therapy approaches and multisensory experiences, such as Namaste. These activities can engage the person with advanced dementia in a close connection with another human being through individualised and sensory based care.

Activity and quality of life

Activity is important for everyone and is associated with improvements in quality of life, happiness, physical and mental wellbeing (Ciro et al., 2015). Engaging in activity can improve relationships, mood and behaviour (Smit et al, 2016). For most individuals with advanced dementia, engaging in meaningful activity will be more beneficial in a one-to-one or small group basis, building on their skills and interests (Stacpoole et al., 2017). One-to one interaction can promote a sense of interest and intimacy that makes a human connection, reducing feelings of existential loneliness (Sjoberg et al., 2018). Activities for an individual with advanced dementia must recognise a person's limited verbal communication and embrace retained abilities. Imaginative practice should focus on the person's remaining assets; these should have a focus on the five senses including vision, hearing, touch, smell and taste (Brown, 2016). Activities can be enhanced by optimising the person's experience of seeing, hearing, touching, tasting and smelling the objects and experiences offered. The person's body experiences, reactions and responses are another asset and the concept of embodiment is valuable in activity for people with dementia (Robertson and McCall, 2018). Based on seminal work by Kontos (2004) embodiment centres on the importance of the body as a way of responding to others and to the environment, expressing needs, even at times rejecting activities and engagement with others. The embodied responses of the person with dementia, both positive and negative, can guide the selection, timing and effectiveness of activity.

In contrast to the sense of wellbeing that is the main ambition of activity, is the distress that can be a feature of advanced dementia. The prevalence of behaviours expressing distress increase as the condition advances (Bougea et al., 2018; Kolanowski et al., 2017). It is important to recognise that the person's distress may be the result of an unmet need that they can no longer communicate (Cohen-Mansfield, 2018). This increases the complexity of identifying and supporting unmet needs and managing distress, in all care environments. The person's dependency within activities and poor cognitive ability can further reduce opportunities for engagement and involvement. Smit et al, (2016) found that people with more advanced dementia in a care setting were less involved in activities than other residents were. It is possible that activities were not offered or did not resonate with the residents. Interestingly, Coll Planas et al., (2017) found that men with advanced dementia living in residential care settings, exceeded expectations of family and staff when actively engaged in football focussed reminiscence activities.

The current policy rhetoric about stress and distress promotes the use of non-pharmacological approaches to support individuals (National Institute for Health and Care Excellence, 2018). While this is a positive policy imperative, it positions non-pharmacological interventions as an alternative treatment for people experiencing distress. In practice, this risks non-pharmacological approaches only being considered when an individual becomes distressed, rather than integrating supportive interventions within day-to day activity. This is reflected in some of the research, evaluating non-pharmacological interventions as outcomes related to the reduction of distress, instead of how these might improve quality of life and well-being (Legere et al., 2018). Additionally, there are common issues in care settings such as high staff turnover, staff absence and burnout, and a lack of opportunity to develop skills and expertise that strongly affect the provision of meaningful activities and caring interventions for people with advanced dementia (Kupeli et al., 2018). Activity co-ordinators in care homes can play an important role; however, they too can be under-resourced, reducing the opportunity for one-to-one activities (Brooke et al., 2016). For people living at home with advanced dementia, family carers and caregivers may struggle to source activities in the face of reduced communication, mobility and responses. Yet, there is a great potential for activity as a non-pharmacological approach to support people with advanced dementia to improve well-being and quality of life (Mansbach et al., 2017).

Accessible Activity

If activities are to have a positive outcome, these should be offered on a one to one basis, relate to the person's physical embodied experience and centre on using as many of the senses as possible. The

activities outlined here, provide strong sensory appeal and have an impact on the movement, reaction and responses of the person's body.

Music-Based Activity

It is theorised that meaningful music and sound can elicit positive memories for a person with dementia, improve their well-being, and reduce stress and distress (Gerdner, 2012). Musical abilities are more accessible than other remaining assets and more independent of other memory systems in advanced dementia (Mercadel-Brotons, 2019). Musical interventions can range from active singing in community choirs and listening to personalised playlists of songs, to more structured, goal orientated music therapy sessions. One four-year long case study highlighted individual and interpersonal benefits of being part of a community choir, including improved social relationships and having a greater sense of meaning (Lamont et al., 2018). However, access to such community-based music activities presents considerable challenges to the person with advanced dementia and their supporters. As dementia advances, modifying active music activities can increase accessibility.

Projects such as Playlist for Life, <https://www.playlistforlife.org.uk/> BBC Music Memories <https://musicmemories.bbcwind.co.uk/> and Music Mirrors <https://www.musicmirrors.co.uk/> encourage individuals, families and carers to connect through music and sound. Playlist for life, for example, provides a framework where a list of songs is produced with family carers, who know the person's previous musical preferences. This is personalised with songs and/or sounds that are meaningful. The evidence base for the use of playlists and personalised music interventions for people with dementia has been increasing over recent years. Research using music as an intervention that showed a reduction in distressed behaviour, included a randomised control trial comparing two groups of nursing home residents (Ridder et al., 2013) and a meta-analysis of 21 studies with data from 890 participants living in care settings (van der Steen et al., 2018). An interactive music intervention can enhance communication and interaction with others, improving the person's quality of life (Mercadel- Brotons, 2019). A recent study including people with dementia who were nonverbal also encouraged the use of music as a way of understanding communication using tone, timing and phrasing of the human voice to engage more deeply. This found that being sensitive to sounds and music used in the care setting, such as reducing excessive noise or using calming sounds further enhanced daily life (Wood, 2020).

Doll Focussed Activity

There is an increase in the use of life-like baby dolls in care, which are similar in weight, size and features to that of a real-life baby. Some dolls can provide multisensory stimulation when perfumed with smells redolent of a newborn baby. Used appropriately, dolls can provide an embodied experience of comfort and warmth and fulfil a need for emotional attachment, by reassuring and soothing the individual (Braden and Gaspar, 2015). However, some research studies have identified concerns about this activity, including conflicts about ownership of the doll in care settings, where a number of residents use these. Some practitioners have also expressed uncertainty about dignity for the person when encouraged to access an object more often associated with children (Mitchell and Templeton, 2014). Therefore, person-centred approaches are of paramount importance to ensure safety and comfort and appropriate reactions to positive or negative responses to the doll. The person's life history about children and childhood and the doll should be explored to increase the likelihood of a positive response. There is promising evidence showing where the doll is accepted, there can be a reduction in distress and an improved connection with the environment of care (Cantarella et al., 2018; Ng et al., 2017).

Animal-Assisted Activity

The use of animals in therapeutic settings has evolved significantly since it first began to appear in literature in the 1980s. Animal-assisted interventions refers to the use of a structured intervention, involving supported interactions between animals and humans, with the aim of providing a therapeutic benefit for participants. Research around animal-based interventions has developed over the years to encompass a wide range of different approaches and groups who can potentially benefit from animal-assisted interventions (AAI).

While anticipated outcomes vary depending on the nature of the AAI, a meta-analysis on the use of AAIs for people with a range of cognitive impairments found a positive impact on reducing distress (Hu et al., 2018). The role that therapy dogs can play in facilitating conversations with people living with dementia has also been noted (Velde et al., 2005). Research from a care home setting suggesting that social engagement improved among 20 residents with advanced dementia who participated in an AAI (Nordgren and Engström, 2014). Most current research concerning AAIs for people with dementia is concentrated on individuals living in care home settings but some early evidence is emerging about the support given by Dementia Assistance Dogs for people living at home (Ritchie et al., 2019). This report showed the importance of the bond and relationships between the dogs and humans in making the experience successful.

Namaste and Sensory Based Activity

Namaste Care is a programme based on developing connections through the senses and has gained considerable momentum in the last decade. The approach consists of a range of interventions and meaningful activities aimed to provide increased engagement and positive communication with the person (Dalkin et al., 2020). The fundamental principles of Namaste Care are to create a calm environment and provide all activities and interactions with an unhurried and loving approach (Stacpoole et al., 2017).

Practitioners, family caregivers, or volunteers can provide Namaste Care and there are a range of learning programmes and literature available. A designated room or space is essential that can be adapted to reflect the tastes and preferences of the individual. Central to the delivery of Namaste Care is that it is not focused on time and sessions can last anywhere from 15 minutes to several hours. Those who are providing Namaste Care are encouraged to perform an activity that the individual is known to enjoy. Examples include; hand massage, aromatherapy, styling hair, providing a wet shave for men, or singing. These activities can be diverse but should be meaningful to the individual. The purpose of doing these activities is for the person in receipt of the activity to feel recognised and valued as a person (St John and Koffman, 2015).

The evidence base regarding the use of Namaste Care in practice is beginning to emerge. This includes an action research study in four out of six nursing homes in the UK, which reported residents with advanced dementia, receiving a programme of regular Namaste therapy, experienced a reduction in their behavioural symptoms, pain and occupational disruptiveness (Stacpoole et al., 2015). An American study including 86 people with advanced dementia from six care homes, found that daily 5-hour Namaste sessions resulted in a significant decrease in withdrawal and agitation (Simard and Volicer, 2010). From the available evidence, Namaste care can support relationship and person-centred care for those with advanced dementia. The implementation of Namaste care in care homes can positively influence the wellbeing of care staff and relatives (Stacpoole et al., 2017). A toolkit is available to support staff and care settings to implement the Namaste Care programme (<https://www.stchristophers.org.uk/wp-content/uploads/2016/03/Namaste-Care-Programme-Toolkit-06.04.2016.pdf>).

While Namaste Care programmes have focussed mainly on residential care settings, the Enhanced Sensory Day Care (ESDC) programme is a sensory-based day service, intended to optimise the wellbeing of people with advanced dementia. It seeks to make connections with the person through a programme that incorporates some or all of the five senses of the body: sight, smell, sound, touch and taste. The activities include; the use of photographs and lights (sight), scented oils and flowers (smell),

music, noise making soft toys (sound), food (taste and smell), and mirroring techniques and responsive movements (touch). Tolson et al., (2015) reported improved quality of life and communication with the participants and care staff and family carers were keen to express how the shared nature of the sensory activities facilitated 'magic moments' in the relationship. It is suggested that wider services, including home-based care, should develop and continue to offer enhanced multi-sensory stimulation for people with advanced dementia to address the current gap in provision.

Complementary Therapies

Complementary Therapies are defined as interventions outside of 'mainstream practice' that can be used alongside conventional medicine (Gunnarsdottir et al., 2018). While poorly defined in the literature, the term 'complementary' is when the intervention, practice or treatment is an accompaniment to the individual's usual care. Complementary therapies integrate an array of different sensory and embodied approaches including touch, smell and sound, placing the individual at the core of the therapy. Activities are tailored to meet the preferences and needs of the individual.

Complementary therapies are currently offered in several healthcare settings for people living with dementia including hospices, hospitals, and long-term care facilities (Lindquist et al., 2018). There has been increasing evidence in recent years for some specific complementary therapies such as body massage, aromatherapy and reflexology. The evidence from research suggests that these could be useful when supporting individuals with dementia who are experiencing neuropsychiatric symptoms and/or are in pain (Anderson et al., 2017; Forrester et al., 2014; Moyle et al., 2014). A positive benefit of complementary therapy is that it is a non-invasive approach with minimal risk (Olley and Morales, 2018). A study by Mitchell (2018) demonstrated the application of massage, reflexology and aromatherapy in an action research study with people who were at the end stage of dementia. The outcomes of this study demonstrated a reduction in a range of neuropsychiatric outcomes for the majority of participants. However, most research studies do not identify if the participants have advanced dementia and therefore caution use in the presence of complex physical care needs

When considering complementary therapy interventions, it is important to understand why it might meet individual needs. The use of touch has been recognised as integral to communicating care, comfort and compassion, so it is important to identify why the intervention may be of benefit to the person (Bensing et al., 2013; Deledda et al., 2013). Not all environments are suitable as there is a need for space that offers privacy, is free from distraction, well lit and accessible (Regan et al., 2019).

Evidence Informed Practice

The lack of research that explores meaningful activity for people in the advanced stage of dementia obscures the prospect of the intended therapeutic benefit of the interventions. The interventions described above can bring meaning to daily life and increased wellbeing to the person with advanced dementia. However, there is a danger that these may be reduced to an activity schedule in some care settings where group activities are organised based on the resources available and skills of the activity co-ordinator. For example, a Care Inspectorate report (2017) found that 55 per cent of care homes in Scotland have provision for ongoing activities every day of the week, but 10 per cent did not provide any opportunities for meaningful activities for residents. A local study in six care homes in England found generally low levels of involvement in meaningful activity (Smith et al., 2018).

The activities explored here do have some evidence but most are from small-scale studies, with limited involvement of people who have advanced dementia. There are multiple factors influencing this limited evidence base, including methodological and ethical challenges linked to the difficulties of research with those who have advanced dementia. As the need for evidence grows so do the calls for positive approaches to practice and the way we conceptualise and respond to evidence informed approaches to advanced dementia (Hanson et al., 2016; Tolson et al., 2017). There is clearly a need for a new policy, practice and research narrative around meaningful activity for people with advanced dementia.

Conclusion

Care settings must meet the rights of people with advanced dementia to participate in meaningful activity, which promotes their health and wellbeing (National Institute for Care Excellence, 2013). A more appropriate selection of activities to improve the quality of life of people with advanced dementia could be supported by embodied and sensory approaches and some examples are provided here. What is important is that activities are carefully considered and person-centred, where knowing the person and understanding their likes and dislikes, speaking to families and exploring the person's life story is crucial. In care settings and at home, a menu of potential activities that the person with advanced dementia can enjoy will enhance not only the family involvement and confidence in care but create satisfying experiences for staff. While those interventions outlined above can enhance the experience of activities for people with advanced dementia, there is a clear gap in the evidence base). This will require innovative and considered research informed approaches and thoughtful ways of dissemination to ensure that research is implemented into practice. Carers and practitioners should be creative and flexible and will require support and training in order to realise the potential of bringing innovative approaches to people with advanced dementia.

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